

Congressional Briefing on Chernobyl

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As the Paul Nemir Professor of international child health for the University of Tennessee Health Sciences Center and the Medical director of the international children's heart Foundation I have had the opportunity to examine and operate on nearly 4,000 children in 20 countries around the world. This unique position provides me with an unusual perspective and has given me a view of congenital heart disease that few in world enjoy. It is from this perspective that I want to share with you an unusual finding we have made in the children with congenital heart disease who live in the areas of the world affected by Chernobyl.

Since 1994 the International Children's Heart Foundation has Made 16 trips to Minsk and Kyiv to operate on children with Congenital heart defects and to provide education and training to local physicians, nurses and technicians. Congenital heart defects occur in approximately 1% of all live births. The total number of children born with heart defects is dependent upon the total population of a country and the birthrate. In Ukraine and Belarus that means that for every one million in population approximately 100 children will be born every year with congenital heart defects. In Belarus that means 1,000 children per year and in Ukraine 5,000 children per year will be born with heart defects. As in the rest of the world, not all these children will require surgery to survive. Approximately 50%-60% of those born with heart defects will require surgery before adulthood. In Belarus that means 500-600 and in Ukraine 2,500-3,000 children will be born yearly who require heart surgery to correct a cardiac defect. These percentages are consistent with the rest of the world. Neither Belarus nor Ukraine noted an overall increase in the percentage of children born with congenital heart defects to the general population following the Chernobyl disaster. However studies conducted by the Ukrainian academy of medical sciences did show an increase in the percentage of children born with congenital defects whose parents were liquidators. The second largest group of defects was congenital heart defects. This increase decreased over the time of the study, which covered the period from 1987 to 1997.

When we made our first trip into Ukraine in 1994 we were asked to specifically help the surgeons with 2 groups of children, those with multiple ventricular septal defects and co-existing pulmonary hypertension and those with a defect known as Ebstein's anomaly. Both of these defects are extremely rare within the overall spectrum of congenital heart defects. Ebsteins's anomaly is known to occur in 12 children per million live births, and children with multiple ventricular septal defects slightly less than Ebstein's. Based upon these rates one would expect that approximately 6 children per year would be born in Ukraine with ebstein's anomaly and only 1-2 in Belarus. Not all children born with Ebstein's anomaly require surgery before adulthood, only approximately 50%, so we would expect that 3-4 children per year would need surgery yearly in Ukraine and 1-2 every other year in Belarus. So, very few surgical cases yearly for Ebstein's anomaly. In

2004 the Amosov Institute of Cardiovascular Surgery in Kyiv undertook a review of all patients who had undergone surgery for Ebstein's anomaly to determine if the techniques we had taught them in 1994 had improved the outcome for these patients. The review encompassed the entire 40 year history of the institute, from 1965 through 2004. We were all delighted to find that the results had improved dramatically after 1994, but what we did not expect to find was that there was a very distinct increase in the number of children with Ebstein's anomaly after 1986. The center had been operating on an average of 3.4 children per year from 1965 through 1986, and this increased to 8.9 per year after 1986. This is more than 2.5 times the number of cases per year receiving operations in the pre-Chornobyl era. One could argue that the improvement in results was the reason for the increase in the number of cases; but there are three points against this argument, 1- epidemiologic studies have repeatedly shown that this is a rare defect and the incidence is consistent around the world and 2- the age of the children declined following Chornobyl, suggesting that these were not patients who had been held back by local physicians for referral after the improved results, 3- the increase was evident before we introduced the techniques that resulted in the improved survival. We have made similar observations in Belarus, but are only now collecting the data.

In conclusion, we have observed what appears to be a significant increase in the number of children born with a rare congenital cardiac defect following Chornobyl which has not previously been reported and believe that a thorough epidemiologic study should be undertaken to determine the etiology.

I would like to thank you for providing me with the opportunity to share this information with you today.